

Supplementary material 1 Details of respondents who submitted questions to the initial survey (n=292)

	Response	Patients/former patients (n=108)	Parents/relatives/friends/partners (n=101)	Professionals (n=83)
Gender	Female	88 (81%)	84 (83%)	57 (69%)
	Male	19 (18%)	15 (15%)	25 (30%)
	Other	0 (0%)	1 (1%)	0 (0%)
	Prefer not to answer	1 (1%)	1 (1%)	1 (1%)
Ethnic group	White	99 (92%)	97 (96%)	73 (88%)
	Asian or Asian British	6 (6%)	1 (1%)	5 (6%)
	Black African, Black Caribbean or Black British	1 (1%)	0 (0%)	1 (1%)
	Mixed/multiple ethnic groups	2 (2%)	0 (0%)	2 (2%)
	Prefer not to answer	0 (0%)	2 (2%)	2 (2%)
	Missing data	0 (0%)	1 (1%)	0 (0%)
	Age (years)	13-15	2 (2%)	1 (1%)
	16-18	16 (16%)	4 (4%)	n/a
	19-24	49 (45%)	5 (5%)	2 (2%)
	25-34	35 (32%)	7 (7%)	9 (11%)
	35-44	3 (3%)	18 (18%)	28 (34%)
	45-54	1 (1%)	42 (42%)	31 (38%)
	55-64	1 (1%)	21 (21%)	12 (14%)
	65+	0 (0%)	3 (3%)	1 (1%)
Country of residence (patients/former patients/parents/relatives/friends/partners) Country of work (professionals)	England	91 (84%)	75 (74%)	67 (81%)
	Scotland	12 (11%)	14 (14%)	7 (8%)
	Wales	3 (3%)	6 (6%)	4 (5%)
	Northern Ireland	1 (1%)	2 (2%)	0 (0%)
	Other	1 (1%)	4 (4%)	4 (5%)
	Prefer not to answer	0 (0%)	0 (0%)	1 (1%)

Cancer first diagnosed with	Hodgkin's disease/lymphoma	29 (27%)	12 (12%)	n/a
	Leukaemia	18 (17%)	22 (22%)	n/a
	Bone tumour (sarcoma)	10 (9%)	13 (13%)	n/a
	Non-Hodgkin's Lymphoma	10 (9%)	12 (12%)	n/a
	Brain or spinal cord	8 (7%)	17 (17%)	n/a
	Soft tissue tumour (sarcoma)	5 (5%)	9 (9%)	n/a
	Ovarian	5 (5%)	1 (1%)	n/a
	Carcinoma	5 (5%)	1 (1%)	n/a
	Thyroid	4 (4%)	1 (1%)	n/a
	Testicular	4 (4%)	1 (1%)	n/a
	Melanoma (skin cancer)	4 (4%)	1 (1%)	n/a
	Colorectal (bowel cancer)	3 (3%)	2 (2%)	n/a
	Breast	2 (2%)	0 (0%)	n/a
	Cervical	1 (1%)	0 (0%)	n/a
	Other	0 (0%)	5 (5%)	n/a
	Not sure	0 (0%)	4 (4%)	n/a
Current situation*	Survivor/Follow-up care	69 (64%)	34 (33%)	n/a
	End of treatment	11 (10%)	8 (8%)	n/a
	On treatment	5 (5%)	19 (19%)	n/a
	Relapsed	4 (4%)	1 (1%)	n/a
	Palliative and end of life care	0 (0%)	1 (1%)	
	Deceased	n/a	32 (31%)	n/a
	End of treatment, Survivor/Follow-up care	14 (13%)	1 (1%)	n/a
	On treatment, Relapsed	2 (2%)	3 (3%)	n/a
	On treatment, End of treatment, Not sure	1 (1%)	0 (0%)	n/a
	Relapsed, Survivor/Follow-up care	1 (1%)	0 (0%)	n/a
	End of treatment, Relapsed	1 (1%)	1 (1%)	n/a
	Not sure	0 (0%)	1 (1%)	n/a

*Participants could select more than one response